



**American Brain Coalition
Spring Membership Meeting Minutes
April 27, 2009
8:00 – 9:30 a.m.
Washington State Convention & Trade Center
Room 201**

Attendance:

Dr. Joseph Coyle – Chair
Dr. Francis Kittredge – Past Chair
Dr. Mahlon DeLong – Treasurer
Dr. Jeffrey Samuels – Advocacy Chair & Board member
Robin Elliott – Membership Committee Chair & Board member
Dr. Robert Griggs – Board member & President-Elect, American Academy of Neurology
Catherine Rydell – Board member & Executive Director/CEO, AAN
Mike Amery – Board member & Legislative Counsel, AAN
Dr. Walter Koroshetz – Deputy Director, NINDS
Dr. Emanuel Tanne – Chairman, Intracranial Hypertension Research Foundation
Amy Tanne – Secretary/Treasurer, IHRF
Jessica Tanne – Director of Development & Communications, IHRF
Doug Franklin – President & CEO, Multiple Sclerosis Association of America
Cheryl-Ann Tubby – Assistant Executive Director, American Epilepsy Society
Kathy Hucks – Membership Coordinator, AES
Mary Lou Thompson – President, Benign Essential Blepharospasm Research Foundation
Janet Hieshetter – Executive Director, Dystonia Medical Research Foundation
Karen Ball – President & CEO, The Sturge Weber Foundation
Brian Fisher – Clin. Acct. Exec., Ferver Therapeutics
Kathleen Welker – President & CEO, Tremor Action Network
Dr. Richard Ries – American Academy of Addiction Psychiatry Board member
Mark Cason – Government & Public Affairs Manager, Society for Neuroscience
Lyle Dennis – Partner, CRD Associates
Nicole Greer – American College of Neuropsychopharmacology
Allison Kupferman – Government & Public Affairs Director
Katie Sale – Executive Director

I. Welcome & Introduction – Joseph Coyle, MD, Chair

Dr. Coyle welcomed all members and guests to the Spring 2009 American Brain Coalition Membership Meeting. He introduced the front of the room – Dr. Mahlon DeLong, Treasurer; Dr. Francis Kittredge, Past Chair; Katie Sale, Executive Director; Allison Kupferman, Government & Public Affairs Director; and Dr. Jeff Samuels, Advocacy Chair.

Dr. Coyle informed attendees of the exciting changes in store for the American Brain Coalition and his hopes for enhancing communication (which is elaborated later during the meeting).

II. Approval of Fall 2008 Membership Minutes – Amy Comstock Rick, Secretary

Dr. Coyle asked for approval of the Fall 2008 Membership minutes on behalf of Amy Comstock Rick, Secretary, who was unable to attend the Meeting. The minutes were approved with no changes added.

III. 2009 Financial Update – Mahlon DeLong, MD, Treasurer

Dr. DeLong explained to attendees that the ABC budget is right on target, and reiterated the importance of paying your membership dues.

IV. Membership Committee Update – Robin Elliott, Membership Committee Chair

Robin Elliott explained that the Membership Committee has been making phone calls to a number of potential members, and we continue to increase our membership numbers at each meeting (the Board will be approving the addition of 5 new Associate members and one Observer).

Staff will continue to look into the number of members each of our organizations represented to get an idea of the total number of members the ABC represents.

Robin thanked Kathleen Welker for her suggestion to visit the Exhibit Hall and introduce ourselves to the non-member non-profit attendees. Drs. Coyle, Samuels, Katie, and Allison will be doing this following the Meeting, along with bringing some information on the ABC.

A. New American Brain Coalition Members

B. Potential Member Update

V. Legislative Affairs – Jeffrey Samuels, MD, Advocacy Committee Chair

A. Lobbyist Update – Lyle Dennis, Cavarocchi, Ruscio & Dennis Associates

Lyle Dennis, partner at Cavarocchi Ruscio Dennis Associates and ABC lobbyist, reported on the latest in Congress.

There have been many changes since our fall meeting, with a new President being sworn in and with The American Recovery and Reinvestment Act (ARRA), as well as the omnibus appropriations bill for FY 2009, being enacted.

Economic Stimulus

The ARRA, or economic stimulus bill, provides \$10.4 billion for the National Institutes of Health (NIH), and was a bit unexpected. Initial drafts of the bill only included \$1.9 billion for NIH, but Sen. Arlen Specter (then-R-PA) insisted on an amendment for \$10.0 billion, and NIH is to receive \$400 million of the Comparative Effectiveness Research money. The bill also includes \$3 billion for the National Science Foundation (NSF), which is a significant percentage increase for that agency. The stimulus package

is a two-year research effort, and there are challenge grants for \$500,000 a year. For Go grants, there is no limit. Walter Koroshetz of NIH said that the payline for NINDS, for example, is currently at the 11th percentile, but stimulus money could fund grants for two years up to the 20th percentile. When asked if NIH can spend that money, Lyle pointed out that NIH is only taking those grants that can be recast into two-year grants.

FY 2009 Funding

The FY 2009 Omnibus Appropriations bill was \$410 billion legislation. In the bill, NIH received a total of \$30.3 billion which represents a 3.2 percent increase. NSF received a total of \$6.5 billion, which represents a 5.9 percent increase. Without this bill, the government would be operating at FY 2008 funding levels.

FY 2010 Funding

Looking ahead to FY 2010, President Obama's preliminary budget was released. There was language that talked about doubling the funding for cancer research at NIH, but it didn't address the rest of the NIH budget. The President will release a more final budget on May 5, 2009. Some groups (such as Research!America and the Society for Neuroscience) are asking for a 10% increase in FY 2010. Other groups are uneasy about asking for a 10% increase after the stimulus money. The American Brain Coalition, which is asking for a 10% increase, is taking the position that we do not want to fall off a funding cliff when the ARRA money runs out. We want strong, sustainable increases. Additionally, the president wants to double NIH funding over 10 years. In order to achieve that, such an increase is probably necessary.

Healthcare Reform

Healthcare reform is another big topic right now. There is visible action in the Senate, and the House may roll out a bill soon, as well. There is a group called the G-11, which includes Senators Baucus (D-MT), Kennedy (D-MA), Enzi (D-WY), Grassley (R-IA), and Hatch (R-UT) that is developing the bill. The bill is divided into sections, among them are insurance coverage; prevention and wellness; long-term care; fraud/abuse; and financing. Right now things are relatively quiet. Once there is a concrete bill, there will be something for opponents to protest.

Comparative Effectiveness Research (CER)

Discussion turned to comparative effectiveness research, for which Congress appropriated \$1.1 billion to the Agency of Healthcare Research and Quality (AHRQ). Of that, AHRQ has to transfer \$400 million to NIH and \$400 million to the Office of the Secretary of Health and Human Services (HHS). \$300 million remains at AHRQ. The Institute of Medicine (IOM) might dictate what happens to the money at HHS.

There are a variety of concerns with this research being conducted. For instance, Lyle explained that a pharmaceutical company spends money on developing and manufacturing a drug and then NIH does a study to show it is not more effective than existing treatments. Or, as Dr. Coyle mentioned, there was a study that compared new on-patient and old off-patient antipsychotic medications. The researchers found no difference in efficacy, except for side effects. As on-patient medications are much more expensive than generics, these results could lead insurers to cover only the generic drugs. Walter Koroshetz of NIH says that the landscape for doing CER is uneven. For instance, NIH is working under a definition that does not include the cost. NIH probably

has to explore how things work in a public health model, as well. Other countries with national health systems can evaluate effectiveness, but can NIH do it right without a centralized health system?

Dr. Kittredge was concerned with CER, citing that doing a strict cost-benefit analysis might yield a bad result for the patient. Additionally, Dr. Koroshetz pointed out that minority groups were concerned that they would be excluded and underrepresented in such research. On a similar vein, Dr. Samuels raised the issue of orphan drugs, since these drugs only work on a small number of people and companies might not manufacture it for such a small customer/profit base.

Still, Robin Elliot emphasized the patient interest in knowing which drugs and treatments are more effective, to determine what course of treatment is right for them. Lyle noted that cost rationing could be used to drop coverage of other, more expensive drugs by Medicare and then private insurance companies would follow suit, leaving patients without access to proper medicine. He also pointed out that IOM is preparing a report for the Secretary of HHS. Nutraceuticals were also discussed, as there is no level one research being conducted on them. Lyle affirmed the complexity of the issue, saying that most patients don't disclose that they are taking bee pollen, for example.

There was such a spirited discussion, that Dr. Coyle decided that we ought to send out an invitation to the membership to establish a working group on the issue. Then, the working group would have a conference call to hash out the issue further and see what the ABC could and should do on the issue of comparative effectiveness research.

B. Advocacy Survey Results

Allison Kupferman, Government and Public Affairs Director, shared the results of the advocacy survey conducted in February 2009. The entire membership was asked to fill out a survey, asking them about their various advocacy activities including for what issues they advocate, whether they do a Capitol Hill Day, whether they share Legislative Alerts, how easy they find CapWiz, and whether they want to learn how to advocate on Capitol Hill. Only ten of the member organizations responded. She noted that 5 out of 10 don't distribute Legislative Alerts. Yet, this past year when the stimulus package was being voted on, Allison said ABC had an astounding 7,000 letters sent to Capitol Hill, which was unprecedented. She said that ABC member organizations are clearly capable of mobilizing and motivating their individual members, so the ABC wants to ascertain what motivates such a flurry of activity. Allison asked what makes member organizations take that extra step to distribute Legislative Alerts to their individual members. Similarly, only 3-4 groups out of the 10 were interested in participating in an advocacy workshop. Again, Allison told the group that ABC leadership is trying to determine what types of activities the ABC can do that would bring value to your membership with the organization. She welcomed any suggestions from the group and introduced Dr. Samuels to build upon the survey results with a big picture discussion.

C. Big Picture Discussion

In light of the survey results, Advocacy Committee Chair Dr. Samuels wanted groups to consider sending ABC Legislative Alerts to their members to let their members decide if they'd like to take action and send letters, rather than the member organizations choosing which items to share with their individual members. He also wanted to let member organizations know that the ABC could try to rally the support of other member

organizations when there is an advocacy issue of importance to them, of which another group might not be aware. Dr. Samuels will be making some phone calls to stimulate interest.

A subsequent discussion turned toward issues of membership involvement and the big picture. Dr. Kittredge wanted to know how AAN gets a maximum impact from a coalition. Mike noted that going with large coalitions like Coalition for Health Funding and signing on to their letters is an effective avenue. Lyle said that he hears this in every coalition. He said that you need to increase involvement gradually and showcase the results. Robin Elliot noted that the real engine of advocacy remains the individual disease and we can't fight it. He noted their own advocacy issues, but said that The ABC would benefit from letting the broader agenda be the goal of the ABC and the individual issues will remain with the member organizations. Karen Ball with Sturge Weber pointed out that the ABC should outline what a particular issue could mean to the member organizations. Janet Hieshetter said the ABC should look at the issues that overlap. For instance, the patient perspective on CER is an interesting topic, but one that the ABC could take on that her individual organization couldn't realistically tackle- she sees that as the Big Picture.

D. 2009 Brain Injury Awareness Month Fair – Michael Amery, Board Member

Mike Amery, Board Member from AAN, shared his experience of exhibiting at the annual Brain Injury Awareness Fair on Capitol Hill where he displayed ABC advocacy materials. He said that four Members of Congress and one former Member stopped by the exhibit. He said the event was a great way to meet other traumatic brain injury groups and see their materials. Dr. Kittredge asked what effect Iraq and Afghanistan have on traumatic brain injury. Mike responded that TBI is the "signature injury" of the wars and that appropriations bills for Department of Defense (DoD) and Veterans Affairs (VA) have seen significant increases for TBI care and research. He also said that epilepsy centers of excellence at the VA are now being created as a result of legislation passed last year.

E. Advocacy Training Session

Allison Kupferman invited attendees to stay after the Board meeting for the advocacy training workshop, to provide tips and how-to's for meeting with Members of Congress, whether on Capitol Hill or in the home district.

VI. Next Phases

Dr. Coyle reminded members of the letter he sent with his vision for the American Brain Coalition (which was included in the agenda materials).

A. New Acronym for the American Brain Coalition

Dr. Coyle asked members to use the acronym 'ABC' as little as possible when referring to the American Brain Coalition as it doesn't incorporate the word 'brain'.

B. Web site Renovation & Expansion

Dr. Coyle explained that the web site should be a tool where the public can go to obtain information about the brain and its disorders. There should be numerous links from the

site to the vast amount of information that exists on our members' sites. Dr. Coyle's ultimate goal is for our web site to be the starting point and the central source for patients, physicians, caregivers, and scientists to go to when they are in need of the most current and relevant information for disorders of the brain.

C. Public Relations Projects

Dr. Coyle said that the Coalition's name should be linked to more brain-related events such as Brain Awareness Week and the International Brain Bee. Katie Sale will look into this further, and attendees should contact Katie if they have any other public relations ideas.

D. Patient Advocacy Travel Award Program & Luncheon Following the Meeting

Dr. Coyle explained the importance of having representation from as many advocacy groups as possible at our meetings. It is also important for our members to have the opportunity to network and discuss issues, concerns, and goals.

Katie Sale will send a survey to members asking when the fall meeting should be held (during the Society for Neuroscience Meeting), and raise the possibility of different times (so the meeting doesn't conflict with exhibiting).

E. Foundation or Corporate Sponsorship Opportunities

In order to move to the next phase with a web site renovation, public relations projects, and a patient advocacy travel awards program and luncheon, Dr. Coyle informed attendees that we would need to seek corporate or foundation sponsorship. This is something the board will be discussing during the Board Meeting; however, Dr. Coyle asked for member feedback. Members were in favor of seeking out foundation and corporate support for these initiatives with the disclaimer that we be careful of the conflict of interest. A member suggested we look into insurance companies, as well.

VII. Other Business

Dr. Coyle asked if there is any other business to discuss at this time, which there was not. He then invited all attendees to stay for the board meeting.

Dr. Coyle reminded members that the next meeting will be held during the Society for Neuroscience Annual Meeting in Chicago, October 17-21.

VIII. Adjournment



**American Brain Coalition
Spring Board Meeting Minutes
April 27, 2009
9:30 – 11:00 a.m.
Washington State Convention & Trade Center
Room 201**

I. Welcome & Introduction of Board Members – Joseph Coyle, MD, Chair

Dr. Coyle introduced the board members present:

Dr. Joseph Coyle – Chair
Dr. Francis Kittredge – Past Chair
Dr. Mahlon DeLong – Treasurer
Dr. Jeffrey Samuels – Advocacy Chair & Board member
Robin Elliott – Membership Committee Chair & Board member
Dr. Robert Griggs – Board member & President-Elect, American Academy of Neurology
Catherine Rydell – Board member & Executive Director/CEO, AAN
Mike Amery – Board member & Legislative Counsel, AAN

II. Approval of Fall 2008 Board Meeting Minutes – Amy Comstock Rick, Secretary

Dr. Coyle asked for approval of the Fall 2008 Board minutes on behalf of Amy Comstock Rick, Secretary, who was unable to attend the Meeting. The minutes were approved with no changes added.

III. Approval of New Members – Robin Elliott, Membership Committee Chair

- A. Current Members
- B. New Associate Members

Robin Elliott asked the board to accept the following members as new Associate members within the ABC:

1. American Academy of Addiction Psychiatry
2. American Society of Addiction Medicine
3. Childhood Brain Tumor Foundation
4. Intracranial Hypertension Research Foundation
5. National Alliance for Research on Schizophrenia and Depression

The board approved all new members.

- C. New Observers

The board approved the below Observer.

1. Eunice Kennedy Shriver National Institute of Child Health and Human Development

- IV. Foundation and Corporate Sponsorship Discussion

The board approved seeking foundation and/or corporate sponsorship for a web site renovation and expansion, public relations projects, and patient advocacy travel award program and luncheon. These would be unrestricted funds and would not be used for advocacy.

The board also discussed providing a link from the ABC site to the AAN's patient site – www.thebrainmatters.org. Staff will look into additional links to our members' sites.

A member suggested we look into re-doing the ABC logo so 'brain' is more prominently represented. Jessica Tanne (IHRF) has volunteered to help with this project.

- V. Establishing a Relationship with the National Academies of Practice

Dr. Samuels explained that he was approached by the National Academies of Practice (NAP) to establish a relationship with the ABC. The NAP would like a letter of support for bringing about universal access to health care. Board members felt this was not central to the mission of the ABC, and we should stay away from health care issues. It was also pointed out that the ABC does not have a position on this issue and it would be overstepping our mandate. The board agreed that the ABC would not support the NAP's request.

- VI. Fall 2010 Meeting – ACNP Annual Meeting in Miami Beach, FL (Dec. 5-9)

Dr. Coyle explained that the American College of Neuropsychopharmacology (ACNP) would like to host the Fall 2010 ABC Meeting, which will be held in Miami Beach, FL from December 5-9. Currently, the American Academy of Neurology hosts the ABC's Spring Meeting, and the Society for Neuroscience hosts the Fall Meeting. As the third Organizing member, the ACNP would like to also provide in-kind meeting support. They understand the importance of the ABC Meeting being held during the SfN Meeting when the SfN holds their meeting in DC, but would like to be considered in the rotation on other years.

The Board approved holding the 2010 Fall ABC Meeting during the ACNP Meeting, but will also have an ABC exhibit booth at the SfN Meeting.

All future ABC Meetings will have conference call capabilities so members who are unable to participate in person can participate by teleconference. We will also ask all members to send a local representative from their advocacy group, should they not be available to participate.

- VII. Other Business

- VIII. Adjournment